

## **NICE guideline presentation to the Sheffield ME and Fibromyalgia Group Thursday 24 March 2022**

### **1 NICE: National Institute for Health and Social Care Excellence**

- Guidelines cover Diagnosis and Management. Do not cover causation
- **Guidance** to health professionals – who can still use clinical judgment
- Positive bullet point recommendations+++ And some Do not ...
- Now over 400 guidelines – three years to prepare a new guideline
- Movement towards 'Living Guidelines' for conditions like Long Covid
- Apply in England, Wales, NI and (to some extent) Channel Islands.
- Scotland has the (2010) Scottish Good Practice Statement for ME/CFS. Will NHS Scotland will be implementing the NICE?

### **2 The 2007 NICE guideline on ME/CFS**

- Recommendations based on a largely psychosocial model of causation
- CBT for abnormal beliefs and behaviours
- GET for inactivity and deconditioning
- Opposition++ >> Not fit for purpose >> Resistance from NICE
- Meetings with Professor Mark Baker at House of Lords
- MEA petition >> over 15,000 signatures >> New guideline

### **3 The 2021 guideline development**

- Agreed to replace the 2007 guideline in 2018 >> Scope meetings
- Committee >> 16 health professionals + 5 patient representatives
- Chair: Dr Peter Barry Deputy Chair: Baroness Ilora Finlay
- Reviewed evidence from clinical trials (GRADE), medical experts, patients and charities and took account of their own experiences
- Clinical trial evidence on safety and efficacy >> low or very low quality for both pharmacological and non pharmacological interventions
- We do not have a safe and effective treatment for ME/CFS
- But there is a great deal that can be done to support and help people manage their illness

### **4 The 2021 guideline timeline**

- Committee met 30 times over a three year period
- Working draft approved and sent out for stakeholder consultation in November 2020. Enormous response >> delay in planned publication
- Publication of final version was halted due to objections from Royal Colleges – mainly regarding removal of GET and downgrading of CBT
- Round table meeting held in October 2021 discussed these concerns – leading to some clarifications but no changes to recommendations
- Final version published in October 2021

## 5 Suspecting ME/CFS and Diagnosing ME/CFS (1.2 – 1.4)

- Importance of suspecting ME/CFS (1.2 and 1.3)
- Aim to confirm diagnosis at 3/12 from onset of symptoms in both adults and children
- Diagnostic criteria based on IoM diagnostic criteria > debilitating fatigue + cognitive dysfunction + unrefreshing sleep + post exertional malaise
- Other symptoms may occur – including dysautonomia (OI, PoTS etc)
- Baseline investigations to exclude other explanations
- **Refer to specialist adult or paediatric service/team to confirm diagnosis and advice on management at 3 months**

## 6 Specialist referral services/teams

- Currently a postcode lottery – especially in NI, Scotland and Wales
- *Specialist teams should consist of a range of healthcare professionals with training and experience in assessing, diagnosing, treating and managing ME/CFS. They commonly have medically trained clinicians from a variety of specialisms (including rheumatology, rehabilitation medicine, endocrinology, infectious diseases, neurology, immunology, general practice and paediatrics) as well as access to other healthcare professionals specialising in ME/CFS. These may include physiotherapists, exercise physiologists, occupational therapists, dietitians, and clinical or counselling psychologists.*
- NB: The MEA position is, and always has been, that specialist services/teams should be physician led

## 7 General Management

- **Prepare and provide the patient and their GP with an agreed care and support plan of management**
- **Regular reviews in primary care – every year for adults, every 6 months for children**
- Advise on causes and management of relapses and exacerbations
- Ensure patients and carers have information on ME/CFS, including support groups

## 8 Specific aspects of management

- Activity and energy management in considerable detail
- Exercise management >> where appropriate
- Note the difference between activity and exercise as defined by NICE
- Symptom management >> Other NICE guidelines (disappointing)
- Downgrading of CBT >> psychological support
- Do not offer GET or Lightning Process
- Other Do not offers..... from 2007 are no longer present
- Melatonin no longer carries a paediatric recommendation

## 9 Other aspects of management

- **Children** – safeguarding issues++ to avoid inappropriate child protection referrals; transition to adult services....
- **Severe and very severe ME/CFS** – domiciliary services, going into hospital
- **Aids and adaptations** and other forms of assistance (eg Blue Badges) to help people maintain their independence
- **Social care referrals**
- **Diet and nutrition** – including weight loss and weight gain
- **Education**
- **Employment**

## 10 Implementation of the new guideline

- Role of NICE >> implementation statement
- Challenges ahead >> BACME, Royal Colleges, CCGs
- CCGs >> Integrated Care Systems (ICS)
- Getting the existing specialist services/teams to follow the new recommendations - MEA working on clinical pathways with services
- Establishing new specialist services/teams where none currently exist – working with DoH in Isle of Man on new referral service
- Education and training of health and social care professionals
- Role of individuals, local groups and charities in monitoring implementation and establishing new services
- Forward ME group are collecting information about out of date websites and making contact with clinical leads where necessary

## 11 Resources

2021 NICE guideline (NG 206):

<https://www.nice.org.uk/guidance/ng206/resources/myalgic-encephalomyelitis-or-encephalopathychronic-fatigue-syndrome-diagnosis-and-management-pdf-66143718094021>

MEA summary:

<https://meassociation.org.uk/2022/01/free-booklet-an-me-association-summary-of-the-new-nice-guideline-for-me-cfs/>

MIMS learning module for health professionals:

<https://meassociation.org.uk/2022/01/new-cpd-learning-module-from-mims-learning-on-the-new-nice-guideline/>

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